

Birt-Hogg-Dubé Newsletter

June 2010

Vol.7, No.1

You are receiving this email because you have expressed an interest in BHD. We hope you will enjoy this and future editions. If you do not wish to receive this newsletter, please see the end of the email for instructions.

Second BHD Symposium Update and Video Highlights

We would like to take this opportunity to thank everyone who attended the Second BHD Symposium in Washington, DC, in April. The successful meeting was attended by clinicians, researchers, and families affected by BHD. A lot of interesting data was presented and discussed.

We would also like to thank the European delegates who managed to present data despite being unable to attend because of the Icelandic volcano.

Video highlights of Dr Laura Schmidt's, Dr Bert Zbar's, Dr Frank McCormack's and Joyce Graff's talks are available [here](#).

New Research Funding

The Myrovlytis Trust is delighted to have awarded a grant extension to Dr Ravi Nookala and Professor Tom Blundell. The twelve month extension will support a Masters student and a Research Assistant to continue the structural biological analysis of Folliculin.

BHD Information Pamphlets

A new range of four information pamphlets about BHD has been created and is available [here](#).

The pamphlets are designed to provide an initial introduction to specific areas of BHD Syndrome. Please feel free to print the pamphlets for your own use, or why not give them to interested friends and family. Primary care physicians / GPs might also find the 'Information for Clinicians' pamphlet useful. The range consists of:

- Diagnosis Information
- Lung Symptoms & Treatment
- Skin Symptoms & Treatment
- Information for Clinicians.

Getting to know you!

In this instalment of 'Getting to know you', we're featuring Tim Cash, a PhD student at the Abramson Family Cancer Research Institute, University of Pennsylvania, USA, who recently presented his data at the Second BHD Symposium, as well as the personal experiences of Ruth in the UK who has only recently been diagnosed with BHD Syndrome.

The interviews can be found [here](#).

Feedback for www.BHDSyndrome.org

We are constantly updating www.BHDSyndrome.org to ensure that is **the** primary online reference site for anybody interested in BHD Syndrome. We would appreciate your feedback on the site to let us know what we're doing right, as well as highlighting any areas you think need improving.

If you have five minutes to spare, please head over to our BHDSyndrome.org survey by clicking on a link below and let us know how we're doing!

Families Feedback Survey - [here](#)

Researchers Feedback Survey - [here](#)

If you would like to participate in our 'Getting to know you!' feature, please contact us at contact@BHDSyndrome.org

If you would like to submit information or a topic for the next newsletter, please contact the editor at info@BHDSyndrome.org

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Myrovlytis Trust Birt-Hogg-Dubé Family Alliance